



SCOTTISH HOSPITALS INQUIRY

**Hearings Commencing
20 September 2021**

Day 8
Thursday 30 September
Morning Session

C O N T E N T S

Lacock, Ms Charmaine (Sworn)

Pages

Examined by Mr Duncan

1-115

10:02

THE CHAIR: Good morning everyone. I think we are able to begin with Ms Lacock

Good morning, Ms Lacock. As you are aware, you are about to be asked questions by Mr Duncan, who I think you have had the opportunity of meeting.

A Yes.

THE CHAIR: We will plan to take a break, probably about half past 11, for about 20 minutes or so; but if, for whatever reason, you want to take an earlier break or you need a later break, just give me an indication and we will do that. Just feel able to just decide that you want a break, if you want a break

Now, I understand you will take the oath?

A Yes.

THE CHAIR: Can I ask you to just, sitting where you are, if you raise your right hand and repeat these words after me.

Ms Charmaine Lacock

(Sworn)

Examined by Mr Duncan

THE CHAIR: Thank you very much, Ms Lacock. Now, Mr Duncan.

MR DUNCAN: Thank you, my Lord

Good morning again, Ms Lacock. I wonder if I might begin with just some formal questions; and can I have you first of all confirm that you are Charmaine Lacock and that you live with your partner and your children in West Dunbartonshire; is that right?

A Yes.

Q I think you have four daughters. Is that right?

A Yes.

Q And you're here today to speak about one of them, your second youngest; is that right?

A Yes.

Q And she's currently 5 years old?

A Yes.

Q I think we can see from your statement that she was diagnosed with leukaemia in August 2018 when she was about [REDACTED]?

A Yes.

Q And then treated at the Royal Hospital for Children and the Queen Elizabeth Hospital as an inpatient and outpatient for over two years?

A Yes.

Q We have a detailed statement from you, and I understand that you are content that that forms

part of your evidence to the Scottish Hospitals Inquiry; is that right?

A Yes.

Q But you have come along today to answer some more questions about aspects of your experience; is that right?

A Yes.

Q Do you have a copy of your statement next to you?

A I do.

Q If at any point you want to look at it to refresh your memory on anything, do so. There might be one or two bits of it that I will take you and maybe get you to read as we go through your evidence.

A Yes.

Q Let's start with a bit of background. One of the things we want to do here is to understand who these stories are about. I think I am right in understanding that your daughter has just started primary school; is that right?

A Yes.

Q How she is getting on?

A Yes, she is great. She is loving school. She is struggling a bit with tiredness, and she is a wee bit speech delayed, but I think we will work through it. But she loves school, she likes going to meet her friends and

her teacher. Yes, she is a very lovable thing.

Q You anticipated my next question. What sort of wee girl is she?

A Of all my kids, I said from the start, I can't believe that this happened to her, because she is as soft and sweet as -- the most loving little thing. Everything about her is sugar and spice and all these things, cupcakes and princesses. She is just the most adorable little thing. But towards the end of this, I realised that she is such a wee fighter that I couldn't have done this with any of my other kids. Just her.

Q Now, speaking of other kids. At the point that your daughter was diagnosed, you had a younger daughter as well; is that right?

A Yes, we'd just had a baby that was born premature, so she was just 2 months old at the time.

Q Yes. And as we go through your evidence, that itself must have brought some additional challenges; is that right?

A Yes. Up until today, it's hard.

Q Yes, okay. Let's now move into the story. I think we can see from your statement that in about mid-August 2018, you noticed some lumps,

I think, in the region of your daughter's lymph nodes; would that be right?

A Yes.

Q I wonder if you could maybe take us through what happened, but maybe stop at the point that your daughter is admitted to Ward 2 of the Schiehallion unit?

A Yes. So ■■■ was sitting next to me and we were watching something on the telly, probably some princess-y, and I was rubbing the back of her neck and I have always done this with her. I don't know why, but I have always just rubbed the back of her neck. And I felt three little lymph nodes in the left-hand side and Alfie was sitting there and I was like: "Oh, this is weird, it is not something that I've felt before". And he said: "Okay, fine, maybe take her to the doctor".

So the next morning, I called the doctor. It was a locum at the practice. I took her in and they -- the doctor checked her over. She confirmed the lymph nodes were swollen there and also in her groin area.

She then said to me that she's going to refer her to the children's hospital for some blood tests and at that point there was like a mask going over her face and I thought: "Oh, I saw that". You know, she just had that wee bit of a concerned look, and I thought:

"Oh, that's weird", but okay. And she said: "But I think this is just viral and it will pass, but I am going to put a referral in".

So we went home. ■■■ would play outside for maybe five minutes or so and then she would come in and ask for a nap. We thought it was maybe because there was a baby in the house and she wanted to be the baby; she was very much obsessed with babies, and still is up until this day, and she was just mimicking what the baby was doing

And by the Friday, she would just walk and fall over, and she would grab her head like there was a bolt going through her head. She would just say her head is "sore". And Alfie came in, he had a break in his work and he came in and I was saying to him, I said, "I am concerned about her, I think I should take her back to the doctor". And he said to me: "You just had her at the doctor". And I said: "Yes, I know, but I am concerned about her". So my neighbour came over and said to me, "She looks very pale, I think you should take her to the doctor".

So I called the doctor and then the secretary was saying: "But you just had her here two days ago". And I said, "But if you're not going to see her

today, I'm taking her to A&E, because something isn't right with her." And she said: "I will give you an emergency appointment if you bring her up in 20 minutes or so".

So we went in, we saw ■■■'s own GP and I have to say at this point, bless him, he's never seen her before because she's never been ill before. She's always been healthy. She'd never even had a cold up until that point. She was brilliant

And he found swollen lymph nodes in her groin, under the arms and the neck. And at this point I have already looked up on Google, because I am very much a Google mum, and cancer did come up a lot, that it was a trigger, swollen lymph nodes. And he said to me, "Don't worry about it, my son had the exact same issues a couple of months ago and two weeks later it all resolved, and it was just a viral infection. If it does present over the weekend..." or he said, "It might present over the weekend, it might just be maybe a childhood illness or something like that, but it might come out over the weekend, just give her paracetamol, keep her comfortable and hydrated and it will pass". So we went home.

The Saturday she got up and she had these massive lumps under her

jaw and I was saying to Alfie: "Look, it's the mumps. Okay, fine, we can calm down now, we know it's the mumps". So Saturday she didn't eat much, we gave her paracetamol, kept her hydrated, and just rest.

And then Sunday morning she got up and these lumps were completely gone, there was nothing there and I was saying to Alfie: "This isn't right". I said, "Mumps doesn't disappear overnight. I think there's something else going on here". And me and ■■■ and baby ■■■ went for a nap, this was maybe about just over lunchtime and ■■■ -- we got up and she was saying her tummy is really sore, and I felt her tummy and it was rock hard, like you couldn't even press into her tummy. And I was saying to Alfie: "That's it. I'm taking her back to the doctors". So we called NHS Scotland and they were saying: "Bring her in to the out of hours GP at Gartnavel", so I went up there with her.

We saw a nurse. Again they said it was a "viral infection", but because of her age she will let us see the doctor. So we saw a doctor and before the doctor even touched ■■■, she was saying to me: "I have got real concerns about her", okay? Relief in a sense that somebody is actually listening to you and I think a bit worried, because

what is her concerns? She said: "We are going to check her over". She checked her over. She found a lump in her tummy, and she said, "It's either her liver or her spleen that's enlarged". Have you felt this before? And I said: "I haven't felt it before, but her tummy is rock hard, so I couldn't really feel anything, apart from a complete hard tummy". And she said: "I want you to take her up to the children's hospital immediately. Don't go home, don't go and pack a bag. Just take her up. If you can't drive, I'll call an ambulance, but she needs to go up now."

So I take her up to the children's hospital, to A&E. Again, we saw a nurse and a doctor, and they all were saying: "We think this is just viral". ■ was singing and dancing and playing away. She presented well, apart from small nitty-bitty things. She didn't look like a sick kid, I'm going to admit that. And then I was saying to them, I said: "Can we do a blood test?" And they were like: "Kids this small, we don't really want to do a blood test because it will make them scared of the hospital." But I said: "I'm not leaving here unless you do the blood test". If you do the blood test and they come back clear, then fine, we can go home and we can ride this out as a viral infection.

So they went and saw the consultant, or whoever it was in charge of the A&E unit, and they came back and they said, "Okay". They agreed they will do a blood test just to set my mind at ease. ■ had a few bruises in weird places as well, so they did the blood test. They took us over to CDU and we were waiting there

40 minutes later, the doctor walked in and she said: "Mum, the blood test came back, ■'s white blood cells is quite high". And I was saying to her: "I don't know what you are saying. Are you saying that she's got blood cancer?" And she said: "Yes, the oncologist is on her way. She will come and see you". And this was maybe just after 12 at night, and 15 minutes later Professor Gibson walked in.

Q And what did she say?

A She just said to me that the blood test came back. She said she already had a look at the blood film at that point and she said: "I can confirm that she has definitely got leukaemia". Her blood count was that high. She said, "I can almost confirm what kind of leukaemia she's got based on her blood count, but I will have a meeting with you and dad in the morning and we will then discuss all of these things".

And I was saying to her I am very much a planner, so I need to know what lies ahead. And I was asking her: "What is going to happen?" And she said, "Well, if she makes it to Friday, we're going to try and see if she can make it over the night and make it to Friday because of her blood count being that high, then we'll talk about treatment more tomorrow."

But she was saying that kids with a high blood count, or a blood count of that -- 472,000 was her white blood count, she said: "Kids don't walk in, never mind play, with a blood count that high. They're normally (inaudible) and very, very ill and ... yes".

Q Yes, I think you indicate in your statement, at paragraph 24, that normal would be under 10,000; is that right?

A Yes, yes.

Q And you have just indicated, Professor Gibson was really indicating to you: "We will just have to see if she makes it"?

A If she makes it, yes.

Q And if you will forgive the question, Ms Lacock, how were you feeling when you heard that?

A I was gobsmacked. Honestly, I came to the hospital thinking something was up with her, but I didn't expect that in my wildest

dreams. I remember taking my phone out and I texted Alfie because he was at home with the other three girls and I just texted him: "It is leukaemia". And I switched the phone off and I thought, I can't speak to him. I was just looking at and I thought, "This is it. You're going to die. You're going to go. We just became a family of six and now we're going to go back to a family of five because this is going to be it. How do we get through leukaemia? How do we get through cancer?" I grew up in the 80s. If somebody had cancer, they died. I didn't know there was newer protocols and things, and the survival rates were higher, you know. I thought this was it for us.

Q We can see from the statement that ■ was admitted, I think on 19 August?

A Yes.

Q To Ward 2A of the Schiehallion unit. And we can also see that she made it through the night. And did she start to rally a little bit at that point?

A Like I said, she was never really sick, up until that point, where she would just lie. She would take little rests, but she would still play. When they moved us over at 2 o'clock in the morning, she was still very much awake and the nurses brought some

toys in for her and she was still sitting in her bed playing. So yes, she didn't look like a kid that wasn't going to make it through the night.

Q Yes. But obviously she did and you moved, I think, to the next day discussing the treatment plan with Professor Gibson; is that right?

A Yes.

Q Do you recall Professor Gibson saying anything in particular at that stage about the risk from infection?

A Yes. So she had me and Alfie up. She was very adamant she wouldn't discuss anything with just me; it had to be both of us. So we went in and she was saying that, okay, she confirmed that ■ had cancer, but for us, and she said on this ward, infection is the biggest thing; infection would probably kill her, rather than the cancer. So we had to really step up to protect her, the safety around her, make sure that she doesn't get exposed to any bugs or, yes, just basically to keep her safe and that infection was the real risk here. The cancer we can deal with if we get to treatment, but infection was a risk.

Q What decisions did you and your partner take at that stage then, about the approach that you were going to take to infection control?

A Yes. So we decided that we're not going to let the girls -- we're going to minimise the visitation to her sisters, so they only came in a couple of times over ■'s treatment anyway. They weren't there on a daily basis or even a weekly basis. We decided to shut our business. Alfie had to stay at home and look after the girls. We said "No visitors". Nobody could come and see her at hospital.

We were really trying to lock everything down and I would stay with her all the time. Alfie would stay at home with the girls and we will try and stop. ■ was supposed to start nursery -- this is ■'s older sister -- we put that on hold because we were scared that ■ might go to nursery, pick up bugs that would come back to ■. So yes, we literally shut everything down. We became a paranoid family, isolating from everything to protect ■.

Q Thank you. Now, I now want to move into the various phases of ■'s treatment; and what I think we will do, we will go things chronologically in chunks of time. You have very helpfully given us a timeline at the end of your statement, and I want to begin with really the first month or so, so August and September 2018. And I'm really just trying to get a feel

for your initial experience on Ward 2A in particular

Now, there are a number of things I want to look at in this time slice. If we begin maybe by just getting an overview, first of all, of the most significant things that happened.

I think we can see that on 24 August 2018, there was surgery to fit a Hickman line; is that right?

A Yes.

Q And block 1 of chemo then began?

A Yes.

Q The other thing I think I would like to ask you some questions about, when we get to it, is that we can see that in September -- 23 September I think -- there was a line infection, is that right?

A Yes.

Q And the line was actually stopped and removed; is that right?

A Yes.

Q Right, okay. So the second thing I want to do, then, in this period is to look at some aspects of treatment and care. Now, in your statement, it's at paragraph 29 for those who want the reference and maybe if you want to have a quick look at it as well, Ms Lacock.

A Yes.

Q You indicate that at the start, there was an issue with taking blood by cannula. So presumably this is before the Hickman line?

A Yes.

Q Do you want to just tell us a little bit about that issue?

A Yes. So ■■■, she had a really -- I don't know, yes, her veins wasn't very accessible. So they would come in and they would try to get a vein, obviously to get medication in. If they did get a cannula in, it wouldn't last long, maybe a day, two at the most and then the cannula would stop working.

And we have been saying from very early on, it seems like whenever they take blood out of the cannula, it would block it and the vein would collapse and then the cannula wouldn't work again. So ■■■ was absolutely petrified of anybody coming in with the blood overalls, anybody carrying a blue tray, because she knows in these trays were things that was going to hurt her. So yes, she was absolutely petrified. Obviously they had to get the cannulas in, so sometimes it would take a lot of attempts to get these cannulas in. For a two-and-a-half-year-old baby, this is traumatic: your mum holding you down, for somebody to hurt you. It's not normal. This is the

person that's supposed to keep you safe.

So very early on, I had a wee bit of a breakdown and I was saying to Alfie: "I can't do this anymore, I can't hold her down". They came in, in the middle of the night, trying to take blood in her foot, in her arm. They couldn't get any blood from anywhere. The doctor threw a tantrum, it was a doctor from A&E, and threw his stuff in the basin and just said: "Well, we're obviously not going to get blood from her because she's in fight or flight mode". He walked out. I was left with ■ being upset. Everybody just left and gave us some time. And then the next morning, it was: "The cannula, is it working?" Oh! Okay. So then: "Oh, we need to get a new cannula". They tried three things. Nothing worked.

And then Alfie turned up and I said: "I can't do this anymore. It's too much for me, you take her". And he was like: "Okay, fine, I will take her and hold her". And he was holding her, and I was standing outside the room, her room at that point was just behind the nurses station and I was standing on the other side by the playroom door and I could hear her scream and scream, and it just carried on and on, and then she would get quiet and then

it will start up again and it will get quiet again.

And at one point I just burst into the room, and I said: "That's it, no more, we're not doing this anymore". And he was saying: "Finally, they got it in. But you don't want to see it in". He said: "Just go to the bathroom, you don't want to see it. And she bit all the way through him, being that scared and that hurt, and she can't go anywhere". So she was obviously very upset about the whole incident.

But yes, she just kept on saying after that: "Don't let them near me, don't let them touch me. I'm your baby and just tell them: 'Go away, this is my baby, don't hurt my baby'". So it was very traumatic for her, as it was for me and Alfie. After that, Alfie was saying that he "can't do this". It is an emotional scar that you will carry forever, and he just can't do it.

So he stayed that night with her and I went home and it was very hard being at home and her little shoes are sitting there and her bed is empty and she was not long potty trained and her potty was sitting there; and all these things that belongs to ■, but there was no ■.

So the next day we went back. He was saying to me she was upset, she wouldn't settle. We made the

decision that I would stay with her in hospital because I couldn't cope at home without her, and he would stay at home with the other three girls.

Yes. Looking back now, I think -- I keep on saying that if we have to do it over again, we will do it the exact same way, but there's a lot of regrets along the way. Relationships with the other kids, their emotional well-being, with mum disappearing for months at a time; it's hard. It's hard for everybody. I think we are all going through treatment at the moment and, yes, dealing with the aftermath of this.

Q Thank you very much. I want to ask you also about another aspect, then. The evidence you have just given is very helpful to us, as I'm sure you know. We have had a lot of evidence about what happens when a Hickman line has to be removed and a cannula has to be used; and it's helpful to have your description of a child's appreciation of the use of a cannula.

But I also notice in your statement, you give us some evidence in relation to the impact also of being given a Hickman line, because I think you say that if you get a Hickman line, that involves an operation under general anaesthetic, and for a young child that can be problematic, because

it involves fasting for quite a long time; is that right?

A Yes, yes. So at that point, they would have fasted from 2 o'clock in the morning and as soon as [REDACTED] was admitted to the ward, they started her on steroids and she wanted to eat all the time. She went from a skinny wee thing to a wee plumpy thing in no time, so yes, it's quite hard. The nurses were always joking [REDACTED] was having a picnic three times during the night because she was on these high dose steroids. But yes, it's horrible. Sometimes they would fast you from 2 o'clock in the morning and you won't get taken until 4 or 5 o'clock in the afternoon, depending on what list you are on and if there's emergencies in front of you. But yes, it was a long time to go without food and water.

Q And just another aspect of treatment and care that I wanted to ask you about. Again, it's just to help us understand the context of some of this. You mention that [REDACTED] had to have something called PEG injections or P-E-G injections?

A Yes. So that's just another type of chemotherapy that they put into the leg muscles, yes, the top of the legs. So basically, again you hold her down, there's two nurses and

at the same time there's two injections into her legs.

Q Are those injections via cannula or is it just --

A No, that's just --

Q A syringe?

A Yes, just a syringe straight into the leg with a needle. Very painful.

Q Thank you. Now, I want to move on to a third aspect of this initial period of care and I'm just going to call this topic "protocols and facilities". You say in your statement, Ms Lacock, it's at paragraph 36, you say that you weren't really told what the rules and the protocols on the ward were; and what I wanted to understand was what you meant by that.

A So I got on the ward; around 2 o'clock on Monday morning, after being admitted, and there was lovely nurses. They came in. I was constantly crying. ■ eventually went to sleep. I didn't sleep; I was just sitting up crying the whole night. And they come in and you tell them the story and they say: "Oh, it's fine. When the morning shift takes over, they will take you on a wee tour, they will show you where everything is, they will tell you how everything works here. We're a family here. Everybody looks out for each other".

And then the next morning came and we had the meeting with Prof, but we never had any further -- nobody showed us where the parents' kitchen was, we didn't even know there was a kitchen there until day 3 when somebody mentioned it in the playroom and I was like: "Oh, there's a kitchen here". You can actually go and make a cup of tea for yourself.

I hear other parents say that they were given a leaflet. We weren't given a leaflet at all, nothing. There was nothing to say: rules and regulations basically, if that makes sense.

There was a playroom. We thought a playroom, so when we did bring ■ in, because ■ and ■ was best friends; I mean, it's her sister and it was also her best friend at that point. We thought that there's a playroom; the two of them can go and play in the playroom.

And the first day they let her play there, and then the second day they let her play and the third day somebody came up and said: "Oh, she's not allowed in her, she needs to leave. This is for patients only and this is a sterile environment". And we were like: "Okay, fine. If you'd told us from the start, then we knew. We're not here to cause trouble. We just want what's best for ■ and if you tell us that, then

we can say to ■ and ■: ‘you play in the room and we shut the door and you don't see the playroom’”, so yes --

So we didn't have any of that. There was an incident where we had some packaging. There was a charity that came and they had boxes. They gave ■ a toy and it was a Peppa Pig scribbling toy or something like that. We didn't know what to do with the box, because it was in the door and there was bins, but we didn't know what goes in what bin, and we thought this is a box so maybe they recycle it, so we just put it on top of the bin and there was a suitcase on the side and there was a breast pump because I was still expressing milk for the baby at home.

And the auxiliaries walk in and we were in the playroom at that point with ■ and she walked in and she just went off her head and she was like: “Your room can't like look like that”. And I was like: “What does the room look like?” She said: “There is stuff everywhere, it needs to be accessible for the cleaners”. It is like: “Okay, it is just a suitcase”. Dad just literally walked through the door, he put the suitcase there. Me and ■ was already in the playroom, and he came

over there, so he just brought our stuff in.

So we kind of learned the hard way what the rules was on the ward. And then they were saying that they will get somebody from infection control to come and speak to us, so somebody turned up and she gave us a leaflet and it was the same leaflet that was on the wall in the bathroom, that if your kid has an infection, then -- it is basically the rules around source. If you are put in isolation, then you can't leave the room, hand sanitise, that kind of thing.

Q Sorry to interrupt you, Ms Lacock. Is that then the leaflet that you refer to at paragraph 38 of your statement? Have a wee look at that.

A Yes, yes.

Q So I think therefore, you are indicating to us that, yes, as you put it, “We found out the rules the hard way”; is that right?

A Yes.

Q And are you indicating also that, as far as facilities on the ward were concerned, that's something else you weren't actually told about?

A Yes, we were never -- you know, they said there is a playroom, but there was nothing around.

Even I heard from somebody else's evidence that they were told: "If you play with something, you have to sanitise it and put it back before you leave the room". We were never told that. I have never even seen anybody sanitising anything in the playroom before they leave the room. Kids were just coming in and out.

Q Did ■ like the playroom?

A To start off with, she loved the playroom. I'm going to say maybe the first week or two, she was in the playroom. And then she caught on that the nurses can actually access your lines when you are in the playroom so they wouldn't do it in the hallway. So she became scared of the playroom and wouldn't go into the playroom at all. So she would just let us walk up and down the corridor all day, because she didn't want to be in the room, because that's somewhere that they can catch you and she didn't want to be in the playroom because again it's somewhere that they can catch you.

Q Was walking up and down the corridor all day something that the staff were okay with?

A Yes, we did it during the day, during the night, ■ was small so I would pick her up and carry her, and

we had a drip stand. We were just in single file form walking up and down. So yes, if you weren't in isolation, then you can do that.

Q You mentioned the parents' kitchen and that you only discovered its existence on day 3, I think. Was this a facility that you used?

A Yes, absolutely. Yes, we went in there. The kids weren't allowed in there; but sometimes I would sneak in at 2 o'clock in the morning and we would look at people and cars and taxis driving by. And it's just, you feel institutionalised if you are stuck in a room all the time and it was just to look at people walking around, thinking: there's life out of this, you know? This isn't all there is to life. And I sometimes used to think: "I wish I had your life and I wasn't stuck in this ward".

Q Now, I want to ask you about some other aspects of the facilities on the ward and, in particular, entertainment for the children. I think you mentioned something called the clown doctors?

A Yes. So the clown doctors came, I think it was on a Thursday. They would come and do a round. I think they go through the whole hospital, to be honest. So it would be two doctors -- I don't know if they are really doctors, but they gave

us that impression. They would dress up in clown outfits and they would go round, and they have a wee puppet and things like that, and they would come in, and no one said: "Do a wee show", but they would come and do funny things for the kids for two or three minutes and then they would move on to the next one.

Q Did [REDACTED] like them?

A Oh, [REDACTED] loved them. She was obsessed with them.

Q And the other thing that you mentioned, that I noticed in your statement in a similar context, is you mentioned that there were a number of charities that visited the ward and before you answer, I wonder if we could go to paragraph 66 of your statement, because you set out quite a bit of detail there and it might be quite important to hear all of that. Do you want to have a look at that?

A Yes. Do you want me to read it out?

Q If you would, that would be very helpful.

A Yes:

"There are a number of charities that came to visit Ward 2A. There was Les Hoey which provided toys and iPads for the kids. There was Team Jack that offered music therapy classes

and ... went to those." It must have said "[REDACTED]" there.

Q Yes, sorry. I should have explained that it's --

A Okay.

"They were really good. The hospital radio staff would come to Ward 2A to play games with the kids. There were some smaller charities which came to Ward 2A. One of these brought a snack trolley for the kids [that is Team Jack] and [REDACTED] could get crisps or a fruit shoots. It was not about what the kids got, the charity staff and volunteers tended to be people who had been through what I was going through. It was important to have that to hold on to. When you are told your child has cancer, you think that they are going to die. These people come through the other side and that interaction and support was so important. Even now I think the parents all walk away with some sort of PTSD about the situation you have been put through with your kid, whether they are going to die. You think that every moment is your last moment."

Q Now, as you might be aware, we have had quite a bit of

evidence about the role that the parents' kitchen provided beyond just providing cups of tea and food and, in particular, that it offered somewhere to obtain support.

A Yes.

Q Are you indicating to us in that paragraph that there was another aspect where that sort of support was provided; that parents who had been through this would come back to the ward?

A Yes. Sometimes parents whose kids went through treatment, sometimes they would bring in gifts and they would just walk past and hand out a wee gift, and they would have a conversation with you and said: "My child has been through this and there is hope on the other side" because when you're going -- you don't hear about survivors. You know, there was a couple of things on the ward, on the walls, but we have always said they should have a survival wall and put the feel-good stories on, you know, the kids that came out on the other end.

So you walk on to a cancer ward and all you hear and see and from your experience is death. You don't think that there is a life after this. So to hear these people speaking. You know, Les Hoey, his daughter went

through cancer treatment when she was a teenager. To hear that they come through it and that they can have a semi normal life afterwards was very reassuring for us.

Q Thank you. Now, the next thing I want to ask you about, I'm still just looking at August 2018, I want to ask you a bit about the rooms that and you were in during that period. I think you say at first, you were in Room 7, but you say that you were moved a lot. Is that right?

A Yes. So when she was first diagnosed, she was just behind the nurses' desk, and we later found out that that's kind of where they keep the newly diagnosed children mostly. So she was just behind the nurses' desk, but we were there maybe for a couple of weeks and then they would come in and say: "Oh, you need to move". And it would be short notice. You know, something came up with a room, we need to clean the room. There was people coming in, putting white powder down the drains. Obviously we didn't know what it was. They told us it's part of the cleaning regime. This is just what they do. They dose the drains and --

Q Yes. Sorry to interrupt you, but just to help everybody following this via your statement. I

think it's paragraph 40 of your statement, Ms Lacock. You indicate: "They moved us a lot in Ward 2A." And are you indicating to us just now that you understood it to be something to do with cleaning the rooms; is that right?

A Yes. If there's something, or if there's something that they spotted in the room, they would just walk in and say: "Pack up, we are coming back in an hour to move you, and we are going to take you over to that room". And then somebody would clean that room out. They will move you into there and then they will go and clean your room. It might be a day or so before somebody moves in there again.

Q Now, we have had quite a lot of descriptions and evidence about what a room looks like and I am not proposing to take you through that in any detail just now. You set out a helpful description at paragraph 26, and I do mention that because I think this is the first time we have heard about a room that had a cot in it, but otherwise it would just be a standard room. Is that right?

A Yes

Q And you also say, as others have, that there was a fold-

down bed. Was there a rule in relation to that?

A Yes. The bed had to be up by 9 o'clock in the morning and you can't put the bed down until after 7 in the evening. So I mean, you don't get sleep at night anyway, but you can't have a nap during the day because the bed had to be out of the way, in case the cleaning staff came in, because the cleaning staff never came in and just cleaned the room and left, so somebody would come in and dust a bit and then they will go away and then a couple of hours later, somebody else would come in and take the bins out and then somebody would come and mop the floor. So they were just spread all over the day. There was never privacy anyway to go for a nap, but the rule was that the bed had to be up during the day.

Q That is helpful. Another thing that you mentioned, that other people have mentioned, you mentioned something about the TVs?

A Oh, the TVs didn't work. Yes. If you get them on, the screens was upside down. You can't get them on to anything. I don't think we ever had a TV that actually worked.

Q Yes. How did you feel about that?

A You feel like you are in prison. You are sitting; we were sitting in an inside room. We were looking out. ■ was sitting, she had the nice comfy Schiehallion chair and the big leather recliner. She was sitting in front of the window. The windows was double windows with blinds. The blinds were stuck, so you had about that much that you could see through the blinds (Indicates). So she was sitting there, looking at what's going on in the atrium. There was no interaction. We literally couldn't see daylight. We couldn't see air. You feel like you are in a jail. The news we got was somebody texting us or maybe when Alfie came in, he would say: "Oh, this and this happened out in the real world". And yes, we were just cut off from everything. It felt like you were in prison.

Q Thank you. Now, the next thing, again still looking at this initial period, that I want to move on and think about is your actual experience on the ward. Now, are we to understand that ■ spent quite a bit of time in source?

A Yes.

Q So that would then be, as you have just described it, you would be in the room?

A Yes.

Q With the blinds that were stuck and the TV that didn't work; is that right?

A Yes, yes.

Q Now, finally on this bit of the timeline. Can I ask you some questions about the infection in September 2018? Now, you tell us a bit about that in your statement. It begins at paragraph 41 for those who wish the reference. It's really just paragraphs 41 to 42. By all means have a look at it, Ms Lacock. But I was going to ask you, I wonder if you can just tell us a bit about the infection, how it came about and any other aspects of it?

A Yes. So she was just coming towards the end of her first block, which is induction, and I noticed that she had, on this side, so her port was on the right-hand side, so on the left-hand side of her chest she had little blisters, little yellow spotty things. So we called the doctor in, called the nurse: "What's going on?" We called the doctor in, and they had a look; took some swabs, sent it away. And then they came back and they said: "She's got a ..." First, they said, "No, that was nothing, it wasn't anything serious". And then they came back a couple of days, she's spiked a temperature and they said that she had a line infection

and it was staphylococcus aureus.

Professor Gibson wrote it down for me.

So the plan was, initially she said, it was in the afternoon, around about 6 she came in. Alfie was sitting with ■■■ and she said: "We are going to try ...". My first question was: "Is the line coming out?" because I thought: Oh, we are going back to cannulas and it's just going to be horrible for her again. It was so much easier with the line. They can just take bloods out and administer medicine. There was no pain involved in using her Hickman line. She said: "No, no, I am going to speak to microbiology, but I think we are going to try and treat it with antibiotics first". First she just said: "She's got an infection in her line". She didn't tell us what infection. She said: "We are going to try and treat it with antibiotics, but I am going to call them now and speak to them".

Q Sorry, can I just pause you there. You mentioned that she had written down or she did write down?

A The next day.

Q That was the next day?

A Yes.

Q Fine. So she was going to go off and find out from microbiology whether the line could be saved; is that right?

A Yes.

Q And should we understand that, in the meantime, ■■■ was put on to antibiotics; is that right?

A Yes. As soon as she spiked a temperature, they started her on Gentamicin and Tazocin. She was neutropenic, so that was the protocol. If you are neutropenic, they start you on both. So they went away; she went away.

Q If we go to the next day then. I think you had a further conversation with Professor Gibson; that is right?

A Yes. The same day she actually went away, and me and Alfie was walking with ■■■, because ■■■ didn't want to be in the room. So we were walking up and down the corridors with her. She came running by, this was about 7.30, 8ish at night and she said: "I spoke to microbiology and the line needs come out, so ■■■ is on the emergency list, first thing in the morning". And she just turned around. So she said: "Fast her from 2 o'clock". She turned around and walked away and I was like: "What's happening now?" She was in there an hour and a half ago or so and she was saying: "We are going to try and save the line with antibiotics". What has changed in the meantime, now that she spoke to microbiology? Is my kid going to die?

And that's always the first thing that you think, is: is this the end? You know, is this the beginning of the end?

So she walked away and, yes, there was no reassurance or nothing. The next morning, she came in again and she wrote down the name of the infection and it was staphylococcus aureus, and she was saying: "This is a bug that everybody carries on their skin that managed to get into her line"; and we were just like: "How does it get into the line?" Because that's only medical staff working with the line and it's got a green cap on, to keep the line safe. It's got a plaster on. They keep it clean every time they use it, but she was saying: "It's just one of these things that happened".

Q Yes. So she is going into surgery to have the line removed. Does that mean that she is fasting again?

A Yes, she was fasting from 2 o'clock in the morning and she went in, pretty early in the morning, to get the line out.

Q Okay. So a few hours after she started fasting?

A Yes. I am talking about maybe 9 o'clock-ish.

Q Right.

A Yes.

Q And how was she throughout this?

A Apart from spiking a temperature, she was -- I mean, she wasn't on chemo so she was lying mostly. She wouldn't walk at this point; she wouldn't walk anymore. She complained about needles and pins. Again, it is a side effect of the chemo.

■ wouldn't talk to anybody. She wouldn't talk to me or her dad. She was just lying. At this point we were in the other side, opposite the Teenage Cancer Trust, in her room, and she just wanted the room shut, the door shut, the window shut, the blinds shut. Her head was constantly sore. She wouldn't speak to anybody. When dad left, she would cry: "Dad should come back". When dad walked in, she would scream: "Go away, I don't want to see you". She said to me: "Go away and don't come back". If you know ■, that's not like her. She is very much -- I am her security blanket. Up until today, she sleeps in my bed. Every night she sleeps in my arm, and she still says: "Keep me safe, don't let anybody touch me", even today.

We asked Professor Gibson: "Could she have depression?" And she just said: "She's too small to have depression", and I said: "But she's not speaking to anybody, she's just lying

there day in and day out". And this carried on for maybe three or four weeks where she wouldn't even look at us. She would ask for food, eat her food and then turn around, not interested in anything.

Q And just to understand, her treatment proceeded at this point. You've indicated that she wasn't on chemo. Did she have chemo orally over this period?

A They did give her chemo orally, yes.

Q But her chemo was paused as a result of the line infection; is that right?

A Yes.

Q Was she given antibiotics for a period as well?

A Yes. So two days before the line went out, she had antibiotics as a precaution, because she spiked and then once they knew that the line was coming out, they had to treat her with another seven days of antibiotics afterwards.

Q Did she eventually start to improve?

A Yes. That bit became better and then we got towards the end of where she could actually go home. But she was still very withdrawn. Emotionally she wasn't there. She didn't want to be there. She

obviously felt cut off from everybody and cut off from the world.

Q Thank you.

A Physically, you know, she also had an anal fissure that was making life hard for her.

Q Yes. We can see what you say in your statement about that.

A Yes.

Q I am going to move on, then, to the next section of the timeline and I'm going to break it down again, if I might, to late September 2018 and October 2018. And again, if I can just start with an overview, so we can just understand the key events. We can see from your statement that ■■■ was transferred to Ward 6A; is that right?

A Yes.

Q And she was allowed home for a few days, I think at the start of October; is that right?

A Yes.

Q Readmitted to 6A soon after that; and am I right in understanding that there were no real breaks between her blocks of chemo; is that right?

A At the end of every block, would spike a temperature. ■■■ would always spike a temperature. We were always in the hospital. You know, they would let us out. Well, it's always 5 o'clock that you get out, so they would

come in, in the morning and say: "You can go home", and by the time they get you sorted, it's teatime so you get home for maybe 5, 6 o'clock, because we only lived ten minutes from the hospital. And then 2 o'clock at night she would spike and we would be back in and then the next morning the doctors would come in and be like: "Oh, you are here again". So we hardly had any break. We were in there most of the time.

Q Am I right in understanding also that over this period, I think in October, she had a port fitted?

A Yes.

Q Is that right?

A Yes. Before they let her out for the first time, so that was part of it: we will remove the line, we will give her antibiotics and then we will fit a port and then she can go home.

Q Was there any attempt to restart intravenous chemo before the port was fitted?

A No.

Q So there was no use of cannulas to give her chemo?

A No, they used the cannula to give -- they did one Vincristine through a cannula. And that kind of brought her to the end of her

first block, and that paralleled(?) at the same time with her infection then.

Q Yes, thank you. Now, I'm going to move through some of the detail of all of those matters; and the first thing to look at, then, is the move to Ward 6A. Where were you, when you heard that Ward 2A was closing?

A We were in Ward 2A. Again, the room opposite the Cancer Trust, the very last room on the ward. Alfie was in and our neighbour sent him a text and said: "I heard [redacted]'s ward is shutting and you guys are moving". He showed me the text and I was like: "Oh no, that can't be right". You know, we don't know anything about it. So we looked it up in the media, and we got the information from there.

Q And at that point, did you know that you would be moving to Ward 6A?

A No.

Q When did you hear that you would be moving to Ward 6A?

A Days before; literally. Well, literally the day before, because Prof Gibson was saying, when we found out about the ward closure, the first thing we were saying was: where are the kids going to move? Are they going to move to different hospitals? So you know, everybody gets allocated a different team. We didn't

know anything. We were not long into this treatment. We had a relationship with Prof Gibson and I cannot say anything bad about her. She has been amazing. We didn't want to lose that relationship with her. We didn't want to start over somewhere else. We wanted to stay as a group.

So Prof Gibson came in and I was quite upset and I was like: "What's happening? Are we moving? Are we going to get another doctor?" And she said: "No, we're going to see where they can make space for us in the hospital. I don't know where we're going to move, but we're going to move as a group, so the whole ward will move".

We then asked about: "What about other services, like scans, the dental, radiology? She was saying: "Those people will stay here because obviously this is where they are set up to work, but we will move. Wherever we move, we will stay as a group and as a unit and we will move there".

Q Did you have any concerns about the fact that some services weren't going to be moving?

A Yes, because we only shut our business to protect [REDACTED]. We only shut out all our friends and everything to protect [REDACTED]. And then we didn't know where we were going to

go. At that point, we were hoping that they will make space for us somewhere in the children's hospital. There was rumours that we might move to the adults hospital and we were like: "No, they can't". Because how do you move a neutropenic child from the adult hospital to access a heart scan in the children's hospital? That's just --

Q Is that the point that you are making about --

A -- foolish.

Q Are you drawing a comparison with all the steps that you had taken to close down the business and --

A Yes.

Q -- protect [REDACTED] on your side of things, and you were concerned about having to move backwards and forwards between the two hospitals?

A Yes, you know. She would be right in the firing line, being in the adult hospital. So we were hoping that they would make a ward, free up a ward in the children's hospital for us, but that wasn't the case.

Q Yes, it was the adult hospital. And I think in your statement, you indicate that there were some services that didn't move across; is that right?

A Yes. It was just the cancer doctors that moved. The others all stayed behind.

Q From your perception of things, how did the staff manage the move?

A It was chaos. It was chaos. They were packing up things, counting medication. They didn't know much either, from what we -- we were told, or that they told us. They didn't know where we were moving. They were just told that we are moving. So there was people that came on to the ward that wasn't meant to work and they would say that they are coming to help to pack up things, label furniture, like everything was labelled as to where; so the idea was they are going to move you as a room, so they would take you and all your furniture, everything at the same time.

Q And was there a particular order in which they took the patients?

A We were told that they would take them in order of vulnerability. So, yes, ■ was -- initially they said they were going to move them morning, like early morning and late evenings, when there isn't a lot of people in the main hospital.

Q Yes. And I should have said this before. For those who want a

reference for this part of Ms Lacock's evidence, it's paragraph 56 of her statement or thereabouts; yes. So you indicate in your statement, as you have just done, that what you were told was that they were going to move the most vulnerable first?

A Vulnerable first, yes.

Q ■ was second on --

A She was second on the list, yes.

Q And she was neutropenic at that point?

A She was neutropenic, yes.

Q Who was involved in moving ■?

A So obviously we had a nurse. There might even have been two nurses, but I think there was definitely -- there was nurses. We had one of the junior doctors. He had a backpack with oxygen in it, should you need it, so there had to be a doctor with you. There was porters, there was auxiliaries. It was a trail. It must have been a scene for people to see us moving through everything. ■ was in her bed. They wanted her to put a mask on. She was having none of it. She was freaking out. Now they want to put this mask on her. So yes, it was a circus. It was horrible.

Q How did you feel about the fact that you were being accompanied by a doctor who had an oxygen supply?

A Yes, scary, because you imagine anything. Why do we need oxygen? What do you expect? If she turned unwell in the middle of the atrium or the adult part, what are you going to do with the oxygen? Are we going to have a medical emergency in the middle of the hospital, with no services around? Where do we go to? You have all these fears.

Q Now, moving on, then, to the next thing I want to ask you about logically; the obvious thing to look at now would be your impressions of Ward 6A. And you set those out really from about paragraph 58 onwards in your statement. And I'm just going to ask you some questions. I'm not going to go through this in too much detail. Did Ward 6A feel like a children's ward?

A Absolutely not, no.

Q In what way?

A The ward felt dirty, when you walk on the ward. If you go down to Ward 2A, the paint was clean, the ward was clean; the staff worked really hard to make it a children's ward. They were going around, putting stickers on the wall, things like that. But there was

no colour. It was a plain beige ward. There was nothing. There was no play area for the children.

There was no facilities for parents. There wasn't even a fridge where you could put a microwave meal in. There wasn't even a microwave. There was nothing. There was absolutely nothing. It was not kid-friendly at all, no.

Q And did you have any concern about the layout of the ward?

A Yes. At the back of the ward, so you had to walk through the ward, past the nurses' station, towards the back of the ward where they would have day care. And so if my kid would spike a temperature during the day, regardless of what it is, they wouldn't know what it is. So you would bring your infected kid onto the ward and you would walk through all these rooms where people are neutropenic. There was no ventilator, vacuums or pressure rooms, so kids that would isolate in those rooms before were now just in a normal room with the doors shut. Sometimes we would have the door open. Kids would walk past. Sometimes if it's friends, ■ would want to go to the door to see her friend or speak to her friend. Yes, so we have all these infection risks and then somebody would bring a kid onto the

ward and they would walk through the ward and you could basically spread it as you go to day care. So that wasn't the brightest idea.

Q And was [REDACTED] in source much on Ward 6A?

A Yes, she was. When we got on to Ward 6A, [REDACTED] was in source; and the room was so hot. We asked the nurses if they can turn the heating down, because obviously we were in a room too, so you had the afternoon sun which would heat the room up, really hot. And we asked the nurses if they can turn down the heating and she would say: "Oh, we will call up". I don't know where they were calling, if they call up. But she referred to, they would call up to maintenance and they can turn it down. It's not, because we were saying: "It doesn't work on the wall" and she said: "No, no, those are just decorational". But they would call up and they can do it. Apparently, they have what we were made to believe was a control a room. And then hours later we would say: "The room is still roasting". We are sitting there, trying to keep [REDACTED] cool with ice packs and cold cloths and things like that. We were sprinkling the bed, so the bed can be damp, so that she can cool down.

And the whole first day, we were saying: "This room is too hot. We can't

live here. We need to get out. Can you move us to another room?" And they said, "There's no other rooms available. All the rooms are like that on here". So they got somebody from maintenance up. This was around maybe 7ish, 7.30, and he had a probe and he put it into the ventilation and it came back: 30 degrees. And I was saying: "30 degrees?" This is a room with the door shut. There's no fan. You can't open the windows. We're stuck in 30 degrees. This is like being stuck in a car.

And at that point, they were like: "Well, what can we do?" I just opened the door and I said: "This is it. We are opening the door. I don't care if we are in source. We will not go out of the room, but we are opening the door so that we can get some sort of air. So you either move us or the door stays open". And they left us that night with the door open, and at that point [REDACTED] didn't have any symptoms that she should have been in source for about four days already.

And I kept on saying: "So she shouldn't even be in source. She is clear". All her samples that they sent away, nothing came back, so why are we still in source? It wasn't until the next day, one of the nurses came up, and I want to name her because she

was always the one that gets you out, Diane; everybody will know. Diane, she was known as the lady that will get you out of source if she could. She would do everything in her power. And she called infection control and she was saying: "█'s stool samples have been fine for four or five days now, why is she still in source?" And they agreed that we can come out and she walked up to the door, and she just ripped the sign off. That was us out of source and we were like: "Oh, okay, we can go for a walk on the ward". But yes, we spent a lot of time in source.

Q Thank you. Now, I want to ask you about something else, still just in relation to your impression of Ward 6A. You make a number of observations about issues to do with cleanliness on that ward. At paragraph 152, if you have a wee look at that, you mention one issue.

A Yes.

Q Do you want to tell us a bit about that?

A Yes. So █ was taken up. We went through A&E. She spiked a temperature. We went through A&E; got on to the ward at around 1 o'clock in the morning or maybe between 1 and 2. And as soon as we went into the ward, it is dirty. The floors, you can see.

Now, I know everybody has been talking about the gold standard of cleanliness in Schiehallion and I agree: in Ward 2A, I could not fault them, they were excellent. Everything was clean.

But in Ward 6A, it wasn't the case. So we went in. We saw these marks there and went into our room. █ wasn't in source on this particular visit.

So the next morning, while she was sleeping, I thought: "I will jump through the shower", you know, get myself ready for the day. And the shower, it wasn't running out; so the shower was backing up into the room, and there was hair swirling in the shower, over the whole floor, and I made a video of this, and I thought, "this isn't real, this is a flagship hospital and we've got a dirty room". They haven't cleaned the room when somebody else was out and I thought: "Okay, fine". I called the nurse and I was saying: "Look at the shower". And she said: "Oh I do apologise and we will get the cleaners in -- first thing, when they come in". So I cleaned it, because I needed a shower before █ woke up, because I would never leave █ by herself to have a shower.

So I cleaned it up. But I had the video and there was stuff in there. There is like a wee plastic drawer and there was still plasters from the

previous person, like they called it -- now I can't remember what they called it, but it is like a sticker and it would keep the Hickman line so it is not dangling. A seat belt. So there were still seat belts in there from the previous people that was in the room.

And then I got out of the shower, everything was cleaned. I went back into the room, got [REDACTED]. She was up. We went for a walk and we saw everywhere on the floor, there was marks, like coffee slippage. You can see, it's like brown stuff that was spilt and it was, like somebody was spilling as they were walking, so it was spillages everywhere and again I thought: this isn't what we're used to. And I took a picture of it; and I thought: "I'll speak to somebody, I'll speak to Prof when she comes in, because the very first meeting is about: 'infection will kill your kid'", and I'm sorry, but if you came to my house and my house looked like that, you would say to me: "This isn't suitable for [REDACTED]". We work in partnership, so I should be able to come to you and say: "This isn't suitable for [REDACTED]. It's not up to standard".

There was a name tag of the previous child on [REDACTED]'s bed. It was never removed. So we cut that off, again showed the nurses and then cut it off and put it in the bin.

And when they did bring in -- they brought in, not immediately, but maybe it was two or three days later, because we were in on the Tuesday morning and the Friday afternoon, there was an incident with one of the nurses and it started off because [REDACTED] had three cannulas in at that point, and I was saying: "Don't take blood from the cannula". No, she had two in, and I said: "If you take blood from the cannula, her vein will collapse, and the cannula wouldn't work. Just use a small needle, a butterfly needle, what they called it". And the nurse, she came in and she said: "Well, we can't hurt her by using a butterfly needle". You deliberately want to inflict more pain on her? And I said: "But she doesn't feel the butterfly needle but she does feel the cannula, so I am trying to reserve the cannulas to save her from getting this pain".

And she went out and then the staff nurse, or the nurse that was on charge of the ward, it was just a staff nurse, she came in to me and she had a few other people with her, she was very intimidating, came into the ward and she was saying to me: "You are deliberately trying to hurt her and what do you think you're doing? This is what's best for [REDACTED]. If we take the blood from the cannula, this is what we're

going to do". And they basically overrode what I asked for there.

And this was something, I spoke to the advanced practitioner nurse and I was saying to her: "This always happens to ■■■. You take the blood from the cannulas and they go out". And she said: "I understand, we will do bloods with a butterfly needle". And it wasn't like she was even needing bloods. It was just that particular time that she needed blood from a vein, rather than a finger prick.

And yes, so I was angry. I am going to admit, I was angry. They overruled me. They called me all sorts of things, because I want to inflict pain on my kid, and that wasn't the case. So they just went ahead and they took the blood from the cannula.

Q Okay. Now, let's just try and get these two events that you have described into the timeline a little. The first issue with the shower and the hair swirling around, we can see from your statement, it was in March 2019.

A Yes.

Q And I just wanted to ask you about that just now, because we are looking at Ward 6A. That incident that you have just described, about the dispute around the cannula.

A Oh yes, that was a wee bit later.

Q That was later; thank you. Now, if we go back then to 2018 and just stay with, then, the impression of Ward 6A, and just on this question of cleanliness. We can see, still at paragraph 152, you mention another issue to do with cleanliness. Now, I'm not clear when you say that issue arose or whether it was something that arose on a number of occasions, but you mention that the bedpans could sit in the rooms for a while.

A Yes.

Q Was that something that occurred regularly?

A Yes. So especially if you are in source, because they would class it then as: there could be a possible infection. So any other time, ■■■ would just use the toilet. So if you are in source, then you have to use bedpans, so that they can basically see what your output is or test samples, things like that. So yes, you can't discharge anything. So she needs to use the bedpan and they would just say: "Stack it up". You just stack it up in a wee bundle, in the corner in the bathroom. So yes, it will just sit there until somebody decides that they are going to get it, or you complain about the smell and then they come and get it.

Q Now, I want to ask you a bit about the facilities on Ward 6A. There was no playroom as such; is that right?

A No.

Q But there was a play area?

A If you can call it that. It was two little tables at the entrance of the ward, so you come through the entrance. It's opposite rooms 2 and 3.

Q Yes. I think you have mentioned this at paragraph 63 of your statement, and you also indicate that you felt that there weren't enough plugs in that area; is that right?

A Yes, yes. There was one plug on the room side, so you had to plug your child's machine in there and then the line would run over the room.

Q Over the corridor?

A Over the corridor and, give and take, this isn't a big corridor so if people want to come past, they had to either climb over the line or go underneath the line or you have to move your kid back every time that they --

Q We have had this area described to us already in evidence; I won't take too much time up on it, Ms Lacock. But are we right in understanding it was a small table with

one or two small chairs for children to sit at and draw --

A Yes.

Q -- in the corridor. And you indicate in your statement that, in fact, to get into the wards, you had to go past that area; is that right?

A Yes. To get to the nurses desk, you have to pass these tables. And sometimes the kids will play there and random strangers will walk into the ward, because they would buzz in. The staff would let them in and they would walk through and they would be looking for a different ward.

Q Would somebody going to day care go along that --

A Yes, they would pass the tables, climb over your lines.

Q Paragraph 65 in your statement, you indicate that the lack of facilities on Ward 6A had an impact on morale among parents, I think. Is that fair?

A Yes.

Q And there was nowhere to congregate really?

A No, no. So we saw parents through windows. We would see parents crying, where before -- I will never forget the first day I walked into the playroom, there was another mum, and I was obviously crying all night and she looked at me and she

burst out crying. She said: "I can see myself in your eyes. I know what you are going through. I can feel it". These parents didn't have it; so you come on -- and when I say "these parents", that includes me. I never had the support from other parents then, because we were all locked up in our rooms. We couldn't go to other parents. If you have a newly diagnosed family, they would shut the door, dealing with their trauma, but they wouldn't see kids coming out and that there might be possible hope after this. So you are stuck in a room with a very sick child and all you think is: your child is going to die.

Q Yes. Another thing you mention, in contrast to Ward 2A, is the question of charities coming on to the ward. So the description that you read out from paragraph 66 of all the charities that came on to Ward 2A; you go on to indicate, I think at paragraph 67, that that wasn't a feature of Ward 6A; is that right?

A No, they stopped everything. Nobody could come in. The kids would play at the tables and we would see people delivering bags of toys at the door and then somebody will go in and they have a trolley and they would load up the things and they would take it away, like off the wards,

so I assume they would take it to the children's charity then. But yes, before, people would come and walk around and you would build up a network of cancer parents. That was all stopped. No charities was allowed on the ward. I think up until today, there's very few. I think it's only maybe Jak's Den that is still getting into the hospital. But yes, they stopped everything.

Q The clown doctors, did they still come?

A Oh, the clown doctors came. I think they were part of the hospital charity. The hospital charity still had volunteers that came in. ■■■ didn't want to play with them. She didn't want to play with the play specialists. She didn't have a relationship with any of these people. She was very much just me and her, me and her, and that was her safe place.

Q Now, let's move on in time, then, to November 2018. We can see from your statement that ■■■ started another block of chemo, I think around about 12 November; and you discuss that at paragraph 74. I think you indicate that it was a hard block of chemo?

A It was very hard, yes.

Q But she was discharged home, I think on 17 November; is that right?

A Yes, yes.

Q But soon after that, she became very unwell with what would be diagnosed as mucositis?

A Yes, yes. So the block was high dose methotrexate and ■■■ woke up in the morning. She was up most of the night throwing up, and it looked like coffee that she was throwing up, so we called the ward and they said: "Bring her in, put her in the ward"; and they were giving her fluids. Eventually they gave her IV medicine and then they popped us off to one of the wards on the children's ward, because the ward was full.

Q Yes. Can I just stop you there? I think you indicated that she was on something called high dose methotrexate?

A Yes.

Q Was this the block of chemotherapy where that started?

A Yes.

Q And I think we can see from your statement that, I think, she was admitted to Ward 3B?

A Yes.

Q Would that be in the children's hospital?

A Yes

Q Why was she on Ward 3B?

A There was no rooms in 6A.

Q Now, in your statement, between paragraphs 77 and 79, you describe your experiences on Ward 3B. I am not going to go through that in detail, but one of the things you mention is that you were able to get access, I think, to some of the Schiehallion staff there, the advanced nurse practitioner; would that be right?

A Yes, so they would pop in once a day to see you.

Q On Ward 3B, were you and ■■■ effectively confined to your room?

A Yes. So because ■■■ was from Schiehallion, they wouldn't let us - - we couldn't walk on the ward. So we were just locked in the room. We had a double door room which was an even darker room. No TVs working, no. So we were just ... yes.

Q Okay. And how was ■■■ at this point?

A Once they had the sickness under control, she was fine. That was the Thursday we went in.

On the Sunday, we asked if we can have a day pass to go out, just to get her out of the hospital for the day. One of the charities, Les Hoey DreamMaker Foundation, had a charity party, so we took ■■■ there.

She wasn't neutropenic, because she was ready for her next dose of treatment, so we thought, we don't know if we are going to see Christmas or if we are even going to have another year with her, so we are just going to take her to this party and let her be a child and be with her sisters. Even at the party, we kept them together.

So yes, we asked for a pass. We never told them where we were going. The advanced nurse practitioner, she said: yes, yes, go, have her back by 4. And I said: how about 5? And she said: okay, fine. Have her back by 5. Then she said: oh, where are you going? And I said: "We are going to the DreamMaker Foundation Christmas party". She said: "You didn't tell me that". I said: "No, you don't know anything, we are just going off".

And so we went ,and ■ had a blast. She loved it; there was princesses and everything. And then we went back on Sunday night.

Monday, we were moved back up to the Schiehallion, which was now 6A; you can't even call it the Schiehallion. We were moved to 6A and they started -- the whole time, since she was admitted, she was on IV fluids anyway, because she was throwing up, so they were thinking there is a bit of

dehydration so just keep her fluids up. And when we went to 6A, they started pre-fluids that night, which was about 70mls an hour, and that is in preparation for her going to theatre the next day to get a lumbar puncture and then before you go to theatre, they would hand you another bag of methotrexate.

So you would go from 6A to the children's hospital with this dose of high dose chemo hanging on your drip and the nurse will go with you, and there would be somebody in case there's any breakage or slippage on the way from obviously this high dose chemo that you are taking. So yes.

Q Yes. So I think looking at your timeline, I think it was about 25 November that ■ went back to 6A.

A Yes.

Q To restart chemo. So let's move then into December. We know that ■, I think, was discharged on 24 December. But before that, I think there was some sort of discussion with Professor Gibson about a Facebook post; is that right?

A Yes. So ■ was in her second round of high dose methotrexate. She took really unwell. What we thought was mucositis, or what was mucositis in the first one,

then just became worse, because she had the second round.

Q Can I stop you there. So the incident that occurred in November that you have just described, there was another incident?

A So that round of chemotherapy had -- so she was due to have, basically, four blocks of high dose methotrexate in that round. So you have -- that was called intra-maintenance. So her intra-maintenance phase consisted of four rounds of high dose methotrexate.

Q Okay.

A So when she had the second one, ■ didn't excrete. So we came up from Ward 3B, up to 6A. They handed the pre-fluid at 70mls an hour, the night before, and ■ hardly excreted anything. She had a small nappy, because at this point she was back in nappies overnight. And I said to the nurse the next morning, I said to the doctor when they came in, I said: "She is not excreting, there is something going on". And they were saying: "Oh no, it is fine, she might be a bit dehydrated". And I said: "But she is not, because we have been in since Thursday on fluids, so she is definitely not dehydrated".

Q I am sorry to interrupt you again, but just so that we can

identify where this is in your statement. I think it is paragraph 83. Have you got that? Beginning on 26 November 2018.

A Yes.

Q Yes. So I'm sorry.

A Yes. So I was saying to them: "She's not excreting", and they said: "She will be fine, we will keep an eye on it". It was always the same, "We will keep an eye on it". It is never: "Let's prevent it -- we will see how bad it gets and then we will go for it".

So they hung up the high dose methotrexate. Now, the point of the pre-fluid is to rinse the high dose methotrexate out of your system quickly. They hung that up and then took her down to the theatre, all the way back to the children's ward, with the lumbar puncture, intrathecal methotrexate again, and then they brought her back up to Ward 6A and ■ was still not excreting.

So by the evening I was saying: "There is no urine output coming". And they were like: "Oh, we will keep an eye on it, we will keep an eye on it". And by the next morning, 9 o'clock, the doctors came in and I said: "She's had half a small nappy overnight" and they were like: "Oh, maybe you are just throwing it away and you didn't ..." and I was like: "No, she is not excreting".

So one of the junior doctors came in and she said: "We are going to weigh her now and then we will weigh her at-" That was at 12 o'clock. "We will weigh her at 12, and then we will weigh her at 6 o'clock and then we will see if she gained weight and we will know if she is keeping fluids back".

So they did it and she kept almost 800 grams over that period back. And then all of a sudden, it was like: "Oh, she is not excreting, we will give her Lasix and we will get the process going". But because the methotrexate was stuck in her for that long, which it shouldn't, all her soft cells burned, the inside of her mouth, all down her tract. She had an NG tube in, so her whole digestive system, it was all burnt, all the way to her bottom. You know, if we aspirate the NG tube, it was pure blood coming out of that.

Q And am I right in understanding that the methotrexate, was that part of a trial?

A Yes. She was on a trial, yes.

Q And so in November, on two occasions at least, there were quite severe effects upon her?

A Yes.

Q And then I think shortly before discharge on 24 December,

there was some sort of discussion between yourself and the --

A Yes. So I was just getting to that, around the houses

But yes, so Alfie, at this point -- because we never wanted ■■■ to be -- we never really wanted the trial for her. We were always more leaning towards the standard treatments, the treatment that has worked before. So the lady from the trial came in and she said: why don't you randomise and see what you get? I was like: "I don't want high dose methotrexate for her", because anything high dose gives me the fear. And she was like: "Just randomise and see, and if you get something that you don't want, then you can say: 'no, I don't want the trial', we will just go standard treatment".

So we said: "Okay, fine. Let's randomise. We might get lucky and get standard treatment there and then, an easier maintenance". And she came back and she said: "■■■ got high dose methotrexate for intra-maintenance and then in her maintenance phase, she would only have oral chemo".

And me and Alfie was like: "Oh, okay what do we do?" We don't want her to have high dose methotrexate, we are scared of it, but that's four blocks, so that's basically eight weeks that she would have high dose

methotrexate, compared to two years of maintenance where she would have had steroids, Vincristine every month. And it was like: "Right, let's go for it. We are going to go for that block with the methotrexate".

But after the second round where ended up, then, on a morphine driver, just out of it for over a week, me and Alfie were saying: "That's it, we're pulling her off this trial. We will deal with whatever comes in maintenance, but she can't physically go through another round of high dose methotrexate. She will not make it".

So Alfie put something on his social media, saying that: "That's it, we are pulling [REDACTED] off the trial. She's not a guinea pig. At the end of the day, she's still my girl".

And before they released her or discharged her, Prof Gibson called for a meeting with me and Alfie and we were sitting, and she said, "So I was told about this comment on social media". And she would always start by saying, "I am not on social media, but I was told about this comment on social media, and I just want to reassure you that we don't see your child as a guinea pig".

And immediately Alfie knew where that was coming from, but at this point we were angry, we were

upset. Our child has just gone through whatever she's gone through. You know, we just wanted to go home, have Christmas with her. And so Prof said: right, fine, we will calm down, we will go home, have Christmas and then we will meet back on the 27th and we will discuss what we are going to do further on.

Q And was this your own Facebook page or Alfie's?

A That was Alfie's, yes.

Q And would you tend to post things, just so friends and followers, and what not, would know what was going on?

A Yes. I'm from South Africa, so my family is back there mostly.

Q While we are on the subject of Facebook, I think we have seen in a number of there witness statements, there is reference to a parents Facebook page. Is that something that you were involved in?

A I was on it. I wouldn't say I was massively involved in it but, yes, I was on it. It was more of an information page, like: what is the ward number or things like that.

Q Was it useful?

A Very useful.

Q And did the hospital run its own Facebook page?

A At that point, no.

MR DUNCAN: That came later. I think you mention it at paragraph 158.

My Lord, looking at my notes, that might be an obvious point to stop for a mid-morning break.

THE CHAIR: Very well. We will just do exactly that. So we will break for about 20 minutes and if we could be back here for perhaps five to 12. And perhaps Ms Lacock could be allowed to leave. (After a pause) We will sit again at five to 12.

11:34

(A short break)

11:57

THE CHAIR: Mr Duncan.

MR DUNCAN: Thank you, my Lord.

Ms Lacock, I am going to move into 2019, January 2019, and we are round about paragraph 97 in your witness statement, for those who want to follow it that way.

I am just going to mention two things at this point. I think we can see that ■ was admitted to the CDU; is that right?

A Yes, yes.

Q And is that because 6A was closed?

A No. We went in; we called them. Again, she went in for chemo or something. No, sorry, it was

a temperature spike. And we called them and they said, "bring her up", but because it was daytime they said to take her straight to CDU, because they are moving Ward 6A to the clinical decisions unit in the children's hospital.

Q Thank you. I think you indicate in your statement that by this time, you had become aware of an issue to do with something called cryptococcus; is that right?

A Yes, yes.

Q And was it as a result of that that we see in your statement that you asked to have a meeting?

A Yes.

Q And was it your intention that there should be a meeting among the patients, or rather the parents, and the staff; is that right?

A Yes. I called for a meeting because I thought, as parents, if we sit in a group, we can bounce off each other. I might ask something and somebody else can take it up from there. But I thought we might be able to get answers from the hospital, "what is going on?" We asked for a meeting with the health board, not with the medical team. We asked for a meeting higher up, infection control and the health board.

Q And was that request granted?

A No.

Q You indicate in your statement that, nevertheless, you yourself did have a meeting, and was that with Professor Gibson and one of the microbiology doctors; is that right?

A Yes.

Q And is that the meeting that you've referred to in paragraphs 98 and 99?

A Yes.

Q Do you want to tell us a little bit about that meeting?

A Yes. So we got on CDU and we were in the room and then they came in and said: "Just go and wait in this room, a nurse will stay with [REDACTED]". And Professor Gibson and a female doctor from microbiology walked in and she basically just said: "I knew that you will have heard about the --

Q Can I just slow you down a bit. Who said that?

A Professor Gibson. So she was always pushed in front to do the talking on these things. So she would say that: "I knew that you will have heard about the cryptococcus problem in the news, but we just want to reassure you that the hospital is safe, we just moved the children for extra precaution, so we are down here now".

And I was saying to her at that point -- and the reason why I was telling you about [REDACTED] being so ill with the methotrexate is [REDACTED] was, most of November and December, we spent in the hospital and she was neutropenic, and I was saying to her: so you deliberately put my child at risk, being in that hospital, knowing that somebody died over Christmas with cryptococcus or at the beginning of December. And the lady from microbiology said to me that: "That wouldn't affect [REDACTED], because you have to have neutropenic for a long period of time"; and at that point I was saying that she was neutropenic for all the time that she was there. So I don't understand how you can say that. That's just nonsense. And they just said it wouldn't have affected her.

Q Yes. So what was the reply from the microbiologist to those comments from you?

A She just said it wouldn't have affected her.

Q And we also see from your statement, I think it's at paragraph 100, if you just take a moment to look at that, that you also again refer to another discussion that happened during the meeting on 21 January. Is this the same meeting?

A This was the same meeting, yes.

Q Yes. And there was a discussion about ■■■ being on an antibiotic; is that right?

A No, that was a prophylactic anti-fungal that she was on, because I have been on a --

Q Is this the Posaconazole?

A Posaconazole, yes. So I was on a Facebook group, an international Facebook group, and somebody posted that their child had a very serious candida infection. Now we know if you are immune compromised or if you are neutropenic and you get a fungal infection, there's not a lot of chance that you can come out the other end of it, because the way they explain it, it is a biological war, so your body needs to fight it.

And this lady was saying that her child was put on Posaconazole for seven days or something like that; it wasn't even that long, but say a week. And I sent her a message and I was saying: are you sure this is the medication? And she said: absolutely, this is what we have been put on for seven days. And so I went back to Prof Gibson. And first I asked other parents all over the UK, because there is a UK ALL group and I asked them if their

children was on Posaconazole, and they said no. So in this meeting, I asked Prof Gibson about the Posaconazole and she said: "Oh, it's because of the hospital environment and it's prophylactic and all our kids get it, with building works going on and it's just the hospital environment. So the kids get a prophylactic to just protect them".

Q Yes, thank you. And ■■■ had been on the Posaconazole from August 2018; is that right?

A Yes, August 2018 to March 2019.

Q Yes. And the discussion about this, was the microbiologist present during this discussion?

A She was.

Q Yes. And did you have any concerns about ■■■ being on Posaconazole for that length of time?

A Yes. I mean, you hear of anything; whether Azole at the end, medication-wise, can cause hearing issues. We were worried about long-term side effects of Posaconazole.

If this is a drug that they use to treat a life-threatening fungal infection and our kids get it four times a day for months upon end, what is the outcome of this? What is the side effects going to be? And I did raise that with her. I said: "Now, we might not know, but

five, ten, twenty years down the line, these things might come out". And we were never asked if we would consent to ■ getting it. I said in my statement, I am not a hippy mum. If she needs it, she gets it and that's it. But they would just say: "There is her blood pressure medicine, there's her Posaconazole, there's this, there's this". We didn't know. Otherwise we thought it was part of the treatment and when we did ask, they did say it is part of the treatment. All the kids get it.

Q Yes. Whereas your research discovers that you are aware of a case in the United States where somebody was on it for seven days, I think you said?

A Yes.

Q And are you also indicating that you made some investigations about the position in the UK and you did not understand that it was being widely used in the UK; is that right?

A Yes, yes. Even Edinburgh Hospital doesn't use it.

Q And did you have any concerns about the explanation that Professor Gibson gave you for why ■ was on Posaconazole?

A Well, we knew about the issues going on in the hospital at this point already, because basically we

broke Ward 2A, according to them, and we were now in Ward 6A and we broke Ward 6A so that's not -- the ward is compromised. The kids couldn't be there anymore. So there was issues going on. So we did understand what she was saying, but we were concerned. And I have said this before. If she -- when I say "she", it is it's not her. But if we were sat down from the start and said: these are the risks, this is what we suggest, would we have gone for it? Absolutely; we probably would have outweighed the risks against it. But we weren't informed. Our kids were just given this medication.

Q Thank you. Now, let's move on with the timeline a little further; and let's look at January to March 2019. I think at paragraph 104, you indicate there's a further block of chemo that starts; is that the delayed intensification phase?

A Yes.

Q And there is a change in the prophylactic medication at this point; is that right?

A Yes.

Q The Posaconazole is stopped and something called?

A Ambisome.

Q Ambisome, that starts?

A Yes.

Q And again, this is an intense block of chemotherapy; is that right?

A Yes.

Q And ■■■ responded well?

A She was amazing. We couldn't believe it.

Q Until in February 2019, there's another line infection; is that right?

A Yes.

Q I think you deal with that at paragraph 107.

A Yes.

Q And it turns out to be staphylococcus, but a slightly different staphylococcus; is that right?

A Yes. Well, we were told it was the exact same one, but they never gave us a name. They just said it was the same one that she had before, and then we got a letter they sent to our home instead of the doctor, the GP practice, to state that it was a different strain.

Q So there was something that went wrong with the communication around that; is that right?

A Yes.

Q Was ■■■'s chemotherapy stopped at this point?

A Yes

Q But this time she didn't lose her line; is that right?

A No, no.

Q And I think we can see from the statement that she improved, and I think she was discharged on 25 February; would that be right?

A Yes, yes.

Q So moving a little further forward again to March of that year. I think we can see that ■■■ had a blood transfusion. You refer to that in paragraph 109. And I think you say this was her last frontline treatment; is that right?

A Yes.

Q Is this ■■■ now looking like she might be on the home straight?

A Yes. So at the end of frontline, that's when you have -- frontline is when you have all the heavy chemo and then maintenance is just a lower dose, but spread out, a daily dose, but spread out, so it's not as intense; not as big.

Q Thinking about where you had been --

A We never thought we would make it.

Q -- six months before. Yes, that's what I was about to ask you. How were you feeling at this point?

A Oh, we were over the moon. We had her in a little superhero costume and we were just over the moon. We'd got to maintenance. It's such a big thing. The staff, they all tell you: when you get to maintenance, you can start getting your life back to an extent. So we were planning on opening back up our business. [REDACTED] was going to go to school. We were just prepping up for a life again.

Q Yes. And then on 19 March, give or take, [REDACTED] has a temperature spike and she is back in 6A; is that right?

A Yes, yes. That was quite a bad spike. She had rigours. We called them and they said: bring her in immediately.

Q Was she having rigours at home?

A Yes.

Q We have had a description of what rigours are like. And you took her to hospital, admitted to 6A, cultures were taken and I think they came back within 48 hours and it's something called pseudomonas?

A Pseudomonas, yes.

Q And I think we can see from your statement, paragraph 110, that you had a discussion with Professor Gibson --

A Yes.

Q -- about the significance of that?

A Yes.

Q Do you want to tell us a bit about that?

A Yes. So I was told the night before that it was a gram negative infection, because they take two vials of blood when they grow samples. So we knew that it was coming from the gram negative vial. So I looked it all up. Like I said before, I am very much a research mum and what it could possibly be. So pseudomonas was one of the infections that I did read up on

When Prof Gibson came in, she said to me that [REDACTED] has a grower infection and it is a gram negative infection and I was saying to her: "What is the name of the infection?" And she said: "pseudomonas, spelled with a P". And I said: "No, I know how to spell it; that's fine". And she said to me: "This is a life-threatening infection, this is a very serious infection; we don't know which way it's going to go". So at that point she was on two antibiotics, so we are going to add a third antibiotic into it, and then we're just going to wait it out and see how it gets on. And she walked out

Another doctor came in, one of the junior doctors -- well, more junior

doctors under the Prof. She came in and I asked her, because I know, from what I have seen, it is an environmental bug and I asked her: "Is this a hospital-acquired infection?" And she just got all nervous and she went to wash her hands and she said: "I will get Prof to come and speak to you", and she walked out. And about five minutes later, Prof Gibson walked back in and she said: "Upon your question, if this infection is from the hospital water, the answer is no". And I said to her: "I have never asked about the water". I asked: "Is this a hospital-acquired infection?" And she said "No".

Q Now, I think we can see from your statement that ■■■ was given a third antibiotic to add to the two that she was already taking; is that right?

A Yes.

Q And she began to improve; is that right?

A Yes. I mean, apart from the temperature spike, she didn't really take too unwell with it. So yes, so I think it was caught early on, but --

Q Once they started to give her antibiotics, there were no more rigors; is that right?

A Yes.

Q And I think we can see that she had her port taken away by surgery shortly after that; is that right?

A Yes, it was an emergency port removal, yes.

Q But I think she must have been getting to the stage where it was going to be removed soon anyway; would that be right?

A Yes.

Q Now, still in March. I think we can see from your statement, paragraph 114 and onwards, that there was a further possible infection, something called candida?

A Yes.

Q And I think you describe how ■■■ developed some strange marks on her knees and you discovered that this might be another infection. Was that confirmed or not?

A They had a dermatologist there. So first they scanned, they did a scan of the area. That brought up a wee pocket of something, but they wasn't too sure. So they got dermatology down. Prof Gibson wasn't there at this point; she was away in Germany for a conference or something. So dermatology came down. The doctor just looked at it, because I took pictures of it and they made circles around it, how it grew, and then you can see there was a line or a circle and then a line and then it started making another circle; and it was quickly spreading, but it looked

like brown bruises, rather than blue bruises, so old bruises.

And the dermatologist came in and he just looked at it and he was like: "That is a candida infection". So they started [REDACTED] on -- she was already on Posaconazole four times a day, so they added in another anti-fungal, so they added in Ambisome. Again, at this point, [REDACTED]'s neutrophils were very, very low, so she was sitting at 0.2 and we asked the doctors if they will give her some G-CSF, so that's basically to jump-start the bone marrow to make cells, because she needs cells to fight this biologically.

So they went and spoke to Prof Gibson and then they came back and said: "Yes, Prof says it's fine, give her two rounds of G-CSF". So they gave her that as well.

Q Thank you. Now, moving on towards the end of [REDACTED]'s treatment. I think from about 1 April 2019, up until November 2020, [REDACTED] was on maintenance; would that be right?

A Yes.

Q There was an admission in September 2019 which I am going to ask you about in a minute; and I think, am I right in understanding that [REDACTED]'s last chemotherapy was in November 2019?

A 2020.

Q 2020. And that would be maintenance chemotherapy?

A Yes.

Q Thank you. And [REDACTED], she is now on three-monthly appointments; is that right?

A Yes, three-monthly.

Q Now, the admission in September 2019. You deal with it in your statement at paragraph 90 and I think it was again an admission following a temperature spike; is that right?

A Yes.

Q And the reason I wanted to ask you about it was: was there again some issue about the use of cannulas?

A Yes. So we came in to A&E. The protocol would be, because [REDACTED] didn't have a port, so they need access. So we knew she had to get a cannula in. So we went up to the ward and they tried

We got to the ward at 11 o'clock in the morning and they tried eight, nine times and I kept on saying, I said: "It's now 6 o'clock, she needs antibiotics". Because every infection -- or every spike is potential sepsis. They treat it for that. I said: "This is just going to get worse. Can we give her oral antibiotics?" So they went. They said: "No, we have to get a cannula

in". So my rule was, from the start, you get two tries and if you can't get a cannula in, then you go and get somebody a pay grade higher than you, because I have heard of kids being stabbed 30, 40 times a night and I wasn't going to let that happen to ■■■.

So you get two goes and then you get somebody a bit higher. So it ended up, at the end, the anaesthetist, the consultant came in and she had a machine, like a scanner to guide her where to go, and even she couldn't get a vein. They were in her feet, in her arms, everything.

And at this point, ■■■ was 3 and a bit; a little child that's already scared. She's been prodded and poked from 11 o'clock till 7.30, 8 o'clock at night, constantly. Every time she hears they've got outside the rooms, they have a box and they pull down the aprons. Every time she hears an apron goes down, she knows somebody is coming for her. Every time somebody touched the door, she knows somebody is coming for her. She was petrified. She was hiding in the bathroom and she wouldn't come out.

And in the end, they agreed, when this doctor couldn't get it in guided, they agreed with Professor Gibson that they will just give her an

oral antibiotic and they then started her on this oral antibiotic.

And ■■■ was so exhausted. She was just sitting there. The sweat was running off her. She was so tired. She couldn't speak. And all she wanted was a little cuddle from her favourite nurse, Suzie. She took to this nurse for some reason. The nurse had never really given her massive attention but because ■■■ liked princesses and pretty girls, Suzie was that, she was gorgeous and ■■■ loved Suzie and she just wanted Suzie. Another nurse came in.

Now, ■■■ wasn't in hospital at that point since March, so her idea of Suzie wasn't what it was. So she saw another girl, another nurse, and she thought it was Suzie and she asked: she just wants Suzie after the nurse left. So Suzie came in and it was the most beautiful moment, this Suzie. It wasn't Suzie. She came in and she gave ■■■ a cuddle.

And just that moment, I took a picture and the nurse had her head down and she had ■■■'s arms around her neck and it was the most beautiful picture. You couldn't see the nurse's face. You just saw the top bit of her head. And I posted that on my Facebook, and I said: "After being through all of this since 11 o'clock this

morning, all she wanted was a cuddle from her favourite nurse to make this better, to make this go away" and I posted that on Facebook.

And within two hours, I had three nurses in my room to say "Take it down, you are not allowed to put pictures of staff on Facebook". I didn't take it down. I made it private, because I knew they were going to come back and I could show them what I did post, because this is what makes the NHS the NHS; it's caring nurses. I made it private. And then the next morning, I had, Emma Somerville, the charge nurse, she came in and had a discussion with me about this post and I showed her the post and she said "Yes, that was a beautiful post", and I said, you know, "With everything that's going on, I think the NHS can do with a bit more feelgood stories than what they had so far".

And I have always been very vocal about ■■■'s journey and how things go in the hospital, in the media. So for me to put this out there, I felt it was fair. I felt that was a moment that the NHS deserved the credit that they gave. But she just said "No, you can't". And then even Prof Gibson came in a few days later and she said, "Oh I heard you put a picture on Facebook"

and I said, "I took it down, don't worry about it, I took it down".

Q I want to move on now, and that really completes all the questions I have got in relation to ■■■'s care and treatment. I want to move on now and just consider some of your evidence in relation to the issues that you had about the hospital. And I am going to take it in two stages. First of all, I am going to ask you some questions about concerns that you had about the safety of the water supply

I will just start this way. Was this something that concerned you on all of the wards that you were on?

A Yes.

Q And again, just at a very general level: was it something that there was evidence of there being an issue with on all of the wards that you were on?

A No, not really, because we didn't know. Once you go to a different ward that wasn't Schiehallion, they wouldn't have the filters; so they wouldn't act like there was anything suspicious. You know, they didn't have the dosing of the drains. But still all the water was connected throughout the hospital, so I wasn't going to go near it and I was certainly not going to let ■■■ near it.

Q Yes. I think you indicate in your statement, paragraph 129, that more or less from the start, you were told not to drink from the taps because I think you say it wasn't clean for drinking; is that right?

A Yes. When we went in that night, the nurses brought bottles, the night she was diagnosed, they brought bottles of water in and they were saying that: "If you need water to drink, ask us and we will bring bottled water, but you can't use the taps to drink the water".

Q Did they say what it was that was wrong with the water?

A No, they just said that it's just to keep everybody safe, and obviously because of what she's going to go through.

Q And you indicate also that you saw signs warning you not to use the water for certain things; is that right?

A Yes. There were signs up in the rooms to say: "This is a hand-wash only basin". There were signs up in the kitchen to say: "You can't wash your dishes and just in the water", so the dishes have to go in the dishwasher to wash it on a hot cycle. If you make tea, you have to fill the kettle with bottled water, so you can't use the

taps basically for anything apart from hand-washing.

Q I think you also indicate that you saw tractors putting crystals of some kind down the plugs; is that right?

A Yes, yes.

Q And you describe seeing filters at least in the Schiehallion unit; is that right?

A Yes, and when we moved up to 6A, the filters moved up with us.

Q Paragraph 132 of your statement, you might want to just have a quick look at that, Ms Lacock.

A (After a pause) Yes.

Q We are going back to September 2018. But just really to focus on a particular exchange. You say that one of the clinicians asked you a question about ■■■ using a shower.

A Yes. So ■■■, she was fasting for going into theatre to get her line removed, the first time, the Hickman line, and they have a list that they come with, a pre-op checklist, and they would ask: when was the last time she had a bath? And I said, "When she was home". And the doctor said, "So does she not have a bath or a shower in the hospital?" knowing that we have been in for a couple of weeks now at

least. And I was saying: no. I said "I don't bath or shower her in the hospital. We use wet wipes and alcohol and dry foam and things like that to clean her". She didn't have hair, but we don't put her in the water, because I spoke to another mum and she said to me that every time she put her son in the water, he would get a line infection. And I said, "So I don't put her near the water". And he said to me, "If this was my child, I wouldn't put her near the water either".

Q The clinician said that?

A The doctor. It was a junior doctor. It wasn't a clinician; it was a junior doctor. But he said to me, "If his was my child, I wouldn't put her near the water either". And I asked him, "Why don't you tell us this from the start? Then we know where we stand and we can make alternative arrangements."

Q Yes. I mean, that exchange is, as you have said, September 2018.

A Yes.

Q You have been on the Schiehallion ward for a month or so; and you have seen all of these other signs of there being an issue in relation to the safety of the water supply.

A Yes.

Q How did that make you feel, all of those --

A Anxious, anxious. As a parent, one of your rights is to be cleaned as a child. I don't want my child to go a month without a shower or a bath, a bed bath with wet wipes. I want my kid to be able to go and wash her dolly, make a bath for her dolly in the water. I don't want my kid to go into the hospital and say, "Mummy, I'm not going near the water, because I know there's bugs in the water". And up until today, ■ wouldn't wash her hands when she goes to the hospital. She would say, "I know there's bugs in the water, I know I can't go near the water". So we're anxious as parents. Again, like I said, if they had said to us from the start: this is the danger zone, don't go near it, we would know: don't go near it. Buff they haven't. They haven't been open and honest with us, and that's all we want, is open, honest answers and for this not to happen to future kids.

Q I think the signs were indicating to you not to use it?

A Yes.

Q Are you indicating to us that what was missing was the explanation for why?

A Absolutely. If we knew that this was the only place that would

make ■ better and this was the risk, then we could have made an informed decision as parents. But because there was no explanation, that kind of amplified things and it made it worse, because then people start speculating; and the only information we got was out of the media.

Q Now, I'll move on then to other issues with the hospital that you identify. You refer at paragraph 135 to a window falling.

A Yes.

Q Is that something that you witnessed?

A We were in the room. So we just heard the thud.

Q You heard a thud?

A Yes. And then they were saying, the nurses were saying: a window fell out. And then we heard that they were putting scaffolding up.

Q Was it just a thud you heard?

A We just heard a thud, and then obviously everybody was like: oh! But yes, it was mostly the thud.

Q You heard a reaction from people as well?

A Yes, yes.

Q You mentioned something about cladding.

A Yes.

Q What was the issue there?

A So they took the cladding off, or they took the cladding away to work behind it. So at this point, we were still in Ward 2A and they had all the windows. We were in the posh side, so we had an outlook on the adult hospital where the buses and taxi rank is, so we could see people moving about.

Q So you referred to that side as the "posh side"?

A Yes, just for us, because if you are on the other side you are really in the cell, so that's really --

Q That would be looking into the atrium?

A Into the atrium, because you can't really see much, you have to be like that out of your window to see what is going on in the atrium. So we were in the side that you were allowed to have a bit of sunshine and daylight, at that end. And then they came and put scaffolding up and put film, green film over the windows, so we couldn't see out anyway. So we were just back in isolation, into another dark room with nothing. We couldn't see anything.

Q Yes.

A And then they were removing the cladding and fixing things behind it.

Q And did you also have a concern about ventilation?

A They had the HEPA filters, so that's more Alfie's bit; so he will tell you a bit later. My focus, to be honest, was ■■■ and keeping ■■■ safe. Yes.

Q Yes. Let's move on then to look at a different issue: communication. I'm going to start with a general question. In general, how would you assess the effectiveness of the hospital's communication with you, in relation to issues affecting your daughter's care?

A From Professor Gibson's side or the clinical team, they would communicate. So we were always on top of what's happening, medically-wise, with her. From an environmental issue with the hospital, there was no communication. What we heard, we heard in the news. It was always a press release or, you know, it was always a story that breaks on the news and somebody would text us and say: this is what's going on. So there was no communication from the hospital at all.

Q I think you say in paragraph 156, the way you put it is that the teams try their best. So you are indicating therefore, I understand, that the communication from the

clinical teams, you have no issue with; is that right?

A Yes. No, no.

Q If we move then to think about communication on more specific issues. How would you assess the effectiveness of the communication with you in relation to the infections that ■■■ suffered and the question of whether there was any connection between those and the hospital?

A Yes. When we heard about the pseudomonas, I asked Professor Gibson obviously the question: "Was this hospital-acquired?" And she said at that point that she would get somebody from microbiology to come and speak to me. And, I mean, ■■■ was on the ward for nine or ten days in total at that stage, during that stay, and they would say to me: "Oh, infection control said they are coming to you". But up until today, we have not had a meeting with infection control or, yes, they never came. They never came and they couldn't even say that I wasn't there, because I was on the ward all the time. I never left ■■■. I never left the ward. I never even went to the shop without her. So they never came.

Q What about communication, then, in relation to the use of prophylactic medication? How

would you assess the effectiveness of that?

A Non-existent. There was no communication. We were never told this medication was prophylactic. We were told it's part of the treatment, so they later on start children on prophylactic antibiotics as well and at that point, again because we were in a situation where we already had kids on prophylactic fungal treatment, we were saying ■ wasn't one of the children, so she didn't have a port or a Hickman line, so she didn't need prophylactic antibiotics.

And I was saying to parents: "Ask the questions, stand up, ask them: 'why does your kid need this medicine?' Prophylactic shouldn't be there, not in this case, unless we know why".

So parents did ask the question. There was a bit of an uproar and they said: "We don't know where, there's infections in the ward. We don't know where it's coming from, if it's in the roof, behind the walls, underneath the flooring, but there's a spike in infections; and that's why". And one of the parents, she asked Prof Gibson and she said to me that Prof Gibson broke down in tears and she said: "I can't tell you. You go and ask them up

there why your children have to be on this medication".

Q I wonder if I might just ask you a few more questions about some of that. Are you indicating that there was actually a meeting with a number of parents and members of staff present?

A Not as much a meeting, but people who were in the ward would then have that conversation; and because we were on a parents' group, so we would have a conversation on the parents group and we were all saying: "If you are in the ward now, ask the questions".

Q I see.

A So it was individual meetings, but at the same time.

Q I see. So were you yourself present during the discussion that you are talking about?

A No.

Q And were you yourself present on the occasion that you have just referred to, when Professor Gibson became upset?

A No; but that mum is still coming for evidence and she will reference that.

Q How would you assess the effectiveness, then, of the communication with you and other

parents in relation to the concerns you had about water?

A Non-existent.

Q Did it go beyond some signs and a direction to use bottled, rather than tap water?

A I mean, there was no communication. It was just, you know: drink the bottled water and don't use the tap water. It was just a sign on the wall.

Q Whose job would you say it was to communicate with parents about these concerns?

A I would think infection control. I would think it's part of their --

Q You have already indicated today, and you indicate in your statement, that you felt that Professor Gibson was doing quite a lot of the heavy lifting on the communication front; is that right?

A Yes, yes.

Q Was that something that you thought she should be doing?

A No, no. She should be looking after our children and he[redacted]ng our children

I asked, even after the overseeing board was put in place, I have asked for certain information coming out of the ward because when [redacted] had pseudomonas, I know that they were in that room, they were testing,

they were taking water samples, they were taking air samples, because they had a trolley and they had this tube sitting on it and it was running for a bit.

So I know that there were samples taken, and me and Alfie asked for the results of these tests; and then Professor Gibson called me, and I also referred to not having this meeting with microbiology, and she called me; it was an evening. And she was saying to me: "Oh, I heard that you asked some questions to Professor Craig White" and I said: "Yes, I did". And she said, "Well, what is it that you want to know?" I said "What I want to know isn't supposed to come from you. I don't want you to get involved in this side of it. I want you to focus on [redacted] and I don't want my relationship with you to be ruined or to be clouded, because of the environment or other concerns." I said "My beef isn't with you. My beef is with the health board and I feel that they should come and answer my questions". And she said "Well, they will just send it back to me anyway". I said "I'm not sending you any questions, because that's not your job".

Q Yes. You say in your statement, paragraph 174: "Professor Gibson did everything she could for [redacted]"

. Not once do I look back and say she didn't have ■■■'s best interests at heart."

A Yes.

Q How do you feel about the fact that, in addition to that, she was also having to deal with the questions that you and others had about concerns with the fabric of the hospital?

A I think it put her in a very difficult situation, because she obviously did what she could for the kids.

You know, Professor Gibson would be there early mornings, late nights. She's one dedicated woman. And all of this would just put extra pressure on her and, like I said before, it's not her job. She shouldn't feel like - - and she's a very intimidating woman, so she wouldn't feel like it, but she shouldn't be scared to walk into a child's room to speak to you about their medical condition because there is this issue with the environment. Her focus should just be on the kids; as is the team, the nurses. We shouldn't have to go and ask them for information. That information should be there for us before the press gets it.

Q Okay. I want to move on and ask you some further questions about another aspect of

communication. At paragraph 122 of your statement, you indicate that you were involved in a meeting with the then cabinet secretary for health, Jeane Freeman.

A Yes.

Q And I think we know from the evidence that we have heard already, and you refer to it also, that there was a meeting in September 2019; is that right?

A Yes.

Q What is your recollection of that meeting?

A Yes. So there was about 12 families in our meeting; we were in on a Saturday. The health secretary was there. There was somebody up high with nursing. I didn't really take notice of the other people. Our meeting, we wanted to get our point across to her.

She sat. She listened to everybody's story going on and on, all the same stories, a little bit different, but basically all the stories came down; all our issues and concerns. She was sitting there looking like she was shocked to the bone, shaking her head, couldn't believe what she was hearing. Yes, so at the end, she was saying she will get us the answers that we deserve and shocked to the bone

and she wants to apologise that people are going through this.

Q And have you got the answers that you deserve?

A That's why we are here.

Q Now, I want to ask you about another process that you have been involved in, something called a case note review?

A Yes.

Q And I think we can see that you refer to that in your statement, round about paragraph 161. I am not going to ask you to go through this in detail and we have already had some evidence about what the case note review is. ■ was included in the case note review; is that right?

A Yes.

Q And you have had an opportunity to consider the individual report that was prepared in relation to her; is that right?

A Yes. It was just coming out anyway, yes.

Q Yes. And just broadly, can you indicate whether you felt the case note review process was something that gave you at least some answers and some satisfaction?

A Yes, because when I opened it, I opened it and I burst out in tears reading the first page and I was saying to Alfie, I said: many people in

the media said that we are paranoid parents and the hospital is amazing, but looking at the outcome of the case note review, that just confirmed that there is something going on and we are not attention seeking, paranoid, boring parents that just want to be in the limelight. There is definitely something. We are not fighting for nothing, you know? So it just confirmed that there is issues.

Q The report confirmed, or the authors of the report indicated, that they considered that there were links between some infections and the hospital environment; is that right?

A Yes.

Q Now, I want to move on towards the end of your evidence, the conclusion of your evidence today, and I want to just ask you a bit about impact and have you give us some reflections on your experiences.

A So the impact of --

Q If I might interrupt you, sorry. I have probably done that too much already today. But I was going to ask you, first of all, about the impacts on ■.

A Yes. So ■ is nervous, in the sense of: she doesn't like people touching her. She's very affectionate, but on her terms. We always say that ■ doesn't have that, where the other kids

would say "This is my body and you can't come up and touch me", because she would be woken up in the middle of the night, somebody taking blood, somebody working with her.

So we're working really hard on getting her to understand that your body is your own and people shouldn't just come up and touch you, to put that wee barrier there

■ is speech delayed, from my point of view, because she had no interaction with children, she was locked up in a room for weeks at a time where there was no stimulation, apart from your mum and your iPad, so what do you do? She has lots of issues around me being her security blanket. She doesn't like to share me with her sisters, because it was me and her for the majority of her treatment. I was the one, as much as I was holding her down and restraining her for people to get what they want from her or do what they want, I was also the one left with her to console her once they leave the room.

Yes, she still has ongoing tummy issues. That's under investigation. We don't know whether that was from chemo. We don't know whether that was maybe from the Posaconazole long-term. We don't know. So we have a scan booked for that.

Q Yes. You mention that in paragraph 140, that you have a concern that that might be to do with the treatment for the pseudomonas; is that right?

A Yes, yes.

Q You also have a concern about other impacts from the preventive antibiotics that ■ was on.

A Yes. So ■ is very sensitive to light. So if the sun is out, she's always asking for her sunglasses. She wouldn't just play outside in the sun, so she always says that the sun hurts her eyes and her head.

We have noticed her hearing is a bit off. I don't know if it's selective, but we would speak to her and she just wouldn't respond until you actually go and touch her or you go right near to her and speak up; but sometimes, if you sit and talk to her like this, she would speak to you, but if she's a bit further, for instance, if I call from downstairs, she wouldn't hear me. I would have to go upstairs and then she would hear me and come downstairs.

So yes, there's lots of little things that are coming out, but again we don't know whether it's, like I said, the long-term side effects of the chemotherapy or if it's some of the other drugs.

Q I now want to ask you some questions about the impact upon you of the issues that you have been describing; and let me put it this way, let me start this way.

Seeing your child go through gruelling cancer treatment and everything else that you have described in relation to just the treatment of cancer must take a toll on you itself, as well as the family; is that right?

A Yes, yes. I have PTSD. I get panic attacks, flashbacks during the night, ■ being dead.

I wake up numerous times. I would sleep maybe two hours a night and I lie and monitor her to make sure that she's fine. She's not in treatment anymore, so she should be fine; but the first thing when I wake up, I check if she's breathing, because when she was diagnosed, I put her in a box and I thought that we weren't coming through this, because it's cancer.

So when she was diagnosed, the fight that we should have taken on was the fight against cancer. What we did end up with was a fight around the environment with cancer and that time should have been time that we spent with ■, not having to ask for meetings and concerns about the hospital. If that was her last days in

hospital, she should have been able to have a bath. If she wanted to put her dolly in the bath, then she should have been able to do that. She didn't have that. And many other children who passed away didn't have that.

So yes, in my mind, I'm getting therapy now, but if I look at the future, I don't really see a future with ■ yet, because for me she's very much still going through cancer. So yes, it's hard. It's hard.

Q Can you keep going?

A Yes. So my relationship with her sisters has been affected.

My eldest daughter has started counselling not long ago. She's got panic attacks. She's got anxiety around what her sister has gone through, around what her role had to be in the family. She was ■ at the time. She basically had to step up into a caretaker role, because me and ■ were always in the hospital and if it wasn't for chemo, it was because ■ spiked with some sort of an infection. There were many infections or many times she spiked and they just couldn't tell us why she spiked, what was the infection. So ■ is struggling with social interaction at the moment. She managed school for an hour or an hour and a half maybe a day. She's ■, so

she's coming up to exams. We're concerned about the impact on her.

Her sister [REDACTED], she's got issues. She's got anxiety. Every time I take [REDACTED] to the hospital, she will say: "Is [REDACTED] coming back, is [REDACTED] going to die? Are you coming back?" Even with [REDACTED]. [REDACTED] had issues recently where I had to take her to the A&E department, which just worked out to be a Sunday night, so very much the same as when [REDACTED] was diagnosed. We had to go to the out of hours GP and then go up to the hospital with an urgent referral for a scan, because she lost mobility and her speech, she lost speech as well. And they were talking about neurology appointments, like referrals for her and the first thing I was thinking, just tell me that she doesn't have cancer, because I can't go through this again.

Just driving up to the hospital, even taking [REDACTED] for a normal follow-up check-up at hospital, it's petrifying. I cry every time I have to even go to the hospital. [REDACTED] knows that if we go in the hospital and she is sitting in the backseat and mummy cries, and she just sits there and be brave, because we're going there and it's a potential death-trap that I am taking my kid into. If she doesn't have it, she will get it there, and that is how it is in my mind.

Like I said, my [REDACTED]-year-old, she's got lots of separation anxiety. She is angry, very angry that I left her to go and be with [REDACTED]. She was always a mummy's girl and now she's more towards her dad.

[REDACTED] was [REDACTED] months odd. I didn't have that first bonding time with her. [REDACTED] is a daddy's girl. She gets stars in her eyes when she sees her dad, and I feel jealous. I feel jealous that I didn't have that with my baby. So yes, it's hard. It's hard, with a lot of mummy guilt; and yes, we had to do what's best for [REDACTED]. But yes, it comes at a price for everybody else.

Alfie himself, he's struggling as well. Our relationship; we're trying to get things back on track. Yes, so everything was just paused to save [REDACTED], and now we have to deal with getting our lives back and getting these answers, so we can finally move forward.

Q Against all of that background, how do you feel about the fact that [REDACTED] had four infections in the hospital, possibly four infections, and possibly that there's a connection between that and the hospital?

A I feel angry. I feel that that stole time that I could have had with my other girls, and I felt that they put my child's life at risk. I felt that

every time we had to stop chemo for treating an infection, that increased ■■■'s risk of relapse and potentially death. So yes, I felt angry. I'm petrified to think that ■■■ would relapse and we'd have to go back there.

Q I have come to the end of the questions that I have for you, Ms Lacock. Are there any other observations that you would want to make before we conclude?

A No.

Q We obviously have your concluding observations at the end of your statement and we will take those into account when we undertake our further work.

A I just want to say thanks to the staff and Professor Gibson for us still having ■■■. If it wasn't for them, you know. We had our ups and downs. That ward is a very, very lonely place. You are locked up in a room for weeks; so there was frustrations at both ends. They were frustrated with me; I was very frustrated with some of them at times.

Would I do it over for ■■■?
Absolutely. Will I fight the battle for ■■■?
? Absolutely.

But yes, we never set out to fight the hospital. We just want answers as parents and we just want to know that if ■■■ relapses, there would be a safe

hospital for her to go back; because if she does relapse and anything happens to her and she dies from a hospital-acquired infection and I haven't done everything I could, how do I live with myself? And that's another part of the mummy guilt that you would always have.

MR DUNCAN: Thank you very much, Ms Lacock. I don't have any further questions for you. My Lord, those are all the questions for Ms Lacock.

THE CHAIR: Thank you,
MR DUNCAN

Thank you very much, Ms Lacock. Thank you for coming. Thank you for providing your witness statement and thank you for giving your evidence this morning; but your evidence is now completed, and the inquiry will have regard to it, and you are now free to go.

(The witness withdrew)

We will adjourn until 2 o'clock this afternoon.

MR DUNCAN: Thank you, my Lord.

THE CHAIR: We will see each other again at 2 o'clock.

12:56

(End of Morning Session)